

Patient-Held Maternal and/or Child Health Records: Meeting the Information Needs of Patients and Healthcare Providers in Developing Countries?

# Patient-Held Maternal and/or Child Health Records: Meeting the Information Needs of Patients and Healthcare Providers in Developing Countries?

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## Abstract

*Though improvements in infant and maternal mortality rates have occurred over time, women and children still die every hour from preventable causes. Various regional, social and economic factors are involved in the ability of women and children to receive adequate care and prevention services. Patient-held maternal and/or child health records have been used for a number of years in many countries to help track health risks, vaccinations and other preventative health measures performed. Though these records are primarily designed to record patient histories and healthcare information and guide healthcare workers providing care, because the records are patient-held, they also allow families a greater ability to track their own health and prevention strategies.*

*A literature search was performed to answer these questions: (1) What are maternal information needs regarding pregnancy, post-natal and infant healthcare, especially in developing countries? (2) What is known about maternal information seeking behavior in developing countries? (3) What is the history and current state of maternal and/or child patient-held healthcare records, do they provide for the information needs of the healthcare provider and what are the effects and outcomes of patient-held records in general and for maternal and/or child health in particular?*

*Specific information needs of pregnant women and mothers are rarely studied. The small numbers of maternal information behavior results available indicate that mothers, in general, prefer to receive health information directly from their healthcare provider as opposed to from other sources (written, etc.) Overall, in developing countries, patient-held maternal and/or child healthcare records have a mostly positive effect for both patient and care provider. Mothers and children with records tend to have better outcomes in healthcare and preventative measures. Further research into the information behaviors of pregnant women and mothers to determine the extent of reliance on interpersonal information seeking is recommended before expending significant resources on enhanced patient-held maternal and/or child healthcare records including storage on mobile devices. In particular, research is needed to explore the utility of providing targeted health messages to mothers regarding their own health and that of their children; this might best be accomplished through mobile technologies.*

**Keywords:** *Child Health Services, Developing Countries, Information Seeking Behavior, Maternal Health Services, Medical Records*

## Introduction

Around the world in developing nations, maternal and child healthcare has been on the forefront of consciousness for improving the lives of global citizens [1-3]. Though improvements in infant and maternal mortality rates have occurred over time, women and children still die every hour from preventable causes [4-6]. In addition, each country has its own policies and challenges with delivering healthcare to its citizens [7-9]. Various regional, social and economic factors are involved in the ability of women and children to receive adequate care and prevention services [10, 11]. Most importantly, though, is making sure the improvements in maternal and child healthcare and preventative measures in developing countries lead to decreased morbidity and mortality in these vulnerable populations [12-14]. The United Nations (UN) Millennium Development Goals for 2015 include several goals defined by the World Health Organization (WHO) as pertaining to health, particularly in developing countries. These health related goals include: worldwide reduction in maternal mortality by three-fourths and in mortality of children under the age of five by two-thirds from year 2000 levels [15]; forty percent of these childhood deaths are in newborns [16]. Only 19 of the 68 priority countries are on track to reach the health-related goals for child mortality and maternal health [15]. Though many of these struggling countries have been severely impacted by the HIV/AIDS epidemic [17], the major causes of neonatal death continue to be sepsis and pneumonia, birth asphyxia, complications of pre-term birth, tetanus and diarrhea [18, 19]. The majority of these conditions could be prevented or treated with proper pre-natal, childbirth and neonatal healthcare, maternal and child nutrition and maternal education [18].

Given the lack of access to healthcare in developing countries, there have been various measures proposed and enacted to enable patients to become greater participants in their own healthcare [20]. In developing countries, self-care measures are important for empowering people and communities who have limited access to a formal healthcare system to make a difference in their own well-being [19-22]. Medical personnel have worked to improve systems for accurately determining higher risk patients, in particular pregnant women who are most likely to need referral for delivery of their babies [4, 19, 21]. Other healthcare interventions include timely vaccination, treatment for infectious and parasitic diseases and malaria, prevention of nutritional deficiencies, smoking cessation education and prophylactic therapy for HIV/AIDS [16, 18, 21]. Patient-held maternal and/or child health records (PHMR or PHCR) have been used for a number of years in many countries to help track health risks, vaccinations and other preventative health measures performed [23-27]. Though these records are designed to record patient histories and healthcare information and to guide healthcare workers providing care, because the records are patient-held, they also allow families a greater ability to track their own health and prevention strategies [7, 27].

## Objectives

In preparation for a pilot project to transfer a patient-held mother and child health record from paper to a web-enabled cell phone platform, a literature review was needed to help answer these general questions:

- 1) What are maternal information needs regarding pregnancy, post-natal and infant healthcare, especially in developing countries?
- 2) What is known about maternal information seeking behavior in developing countries?
- 3) What is the history and current state of maternal and/or child patient-held healthcare records (especially in developing countries,) do they provide for the information needs of the healthcare provider and what are the effects and outcomes of patient-held records in general and for maternal and/or child health in particular?

The revised (2010) Kenyan *Maternal & Child Health Booklet* provides a good example of a paper record used currently in a developing country [28-31]. This 17-page booklet is larger than many of the other maternal-child records [27], and has room for recording information regarding one pregnancy and child. Most of the seven pages of “Maternal Profile” seem designed for use by the healthcare provider; it includes the medical, surgical and obstetrical history. There are spaces for recording examination findings from first encounter to delivery. A graph for tracking the mother’s weight gain, preventive therapy schedule, family planning chart, and notes section seem to be the main areas for providing for maternal information needs regarding the pregnancy. The “Child Health Card” section of the booklet seems more designed to provide information to the child’s family. On almost every page, there are notes for parents such as immunization and vitamin reminders, developmental milestones, appropriate weight to height chart, retroviral prophylaxis chart and follow-up, notes, and infant feeding recommendations.

## Methods

This study included two related literature searches performed concurrently. Databases searched include: CINAHL Plus, Dissertation Abstracts, EMBASE, Global Health Library, Global Health Archive, PubMed, Science Direct, Social Science Research Network, Web of Science, WHO Library Database (WHOLIS) and WHO Statistical Information System (WHOSIS). For the first query topic the Library, Information Science & Technology Abstracts (LISTA) database was also included. Searches took place in January and February 2011; articles retrieved were limited to the English language literature. The searches were conceptual in nature. Approaching the two questions regarding maternal information seeking and information needs, the first search included the concepts of <maternal or pregnant women’s healthcare/care-giving information behavior (information needs, information seeking)> and <developing countries>. The second search centered on answering the third question regarding patient-held records and their usefulness. This search utilized the idea of <patient-held maternal and/or child healthcare record>, then added in the notion of <outcomes>. The search was expanded by the use of pearl-growing techniques [32]; applying database-specific subject headings or descriptors from a known article to search for related articles [33]. Investigating database-identified related articles, article citations and article reference lists further expanded the search.

Some general search terms were used either combined or separately for each topic. The search terms listed are in a single format, but the format was altered depending on the search criteria and preferential use by each individual database. Search strings were also expanded and contracted depending on the number of results obtained in each individual database, and search terms might include: (“mother” OR “maternal”), (“child”), (“health” OR “medical”), (“information” OR “data”), and (“developing” OR “undeveloped” OR “third world”). To further define the searches, the following terms were added: (“information need\*” OR “information seek\*” OR “information behavior”), (“record” OR “card” OR “booklet”), (“health information system”), (“patient held” OR “hand held”) and (“outcomes”). Articles focusing on behavior of information seeking in specific places, such as the Internet or libraries, were not included. Pearl-growing techniques were especially important for the maternal and child record search. In particular, use of the subject headings and reference list for the 1993, multi-site study, *Evaluation of the home-based maternal record: a WHO collaborative* [24], proved particularly helpful for locating literature on this topic.

## Results

### A. Maternal Information Needs and Information Seeking Behavior

The literature covering maternal information behavior specifically for medical or health related information needs in developing countries seems rather limited. Only eight published papers from six separate studies of information behavior, including health information needs, of women and mothers in developing countries were retrieved using the literature search criteria ([Table 1](#)). Health information needs for family, prenatal and infant care are ranked high in the studies of overall women’s information needs in developing countries [34, 35, 38, 39], and a few studies look specifically at health information seeking behavior in these populations [36, 37, 40, 41]. A few common themes emerge from the available research literature; mothers in the developing countries studied tend to seek medical information and advice for their children and families more commonly than searching for other information needs, and the first source or most common source for information comes from other people. Basic infant and child developmental and care information are mentioned as important to mothers in the studies from Tanzania and Turkey [36, 37, 40].

In order to get a broader view of maternal information behavior, some studies of disadvantaged mothers from developed countries were also included ([Table 2](#)). While these studies come from different countries and regions of the world, they show some interesting similarities as well as trends in the direction of information behavior. Unfortunately, due to the small number of studies and the small number of participants, true generalities cannot be drawn, though comparisons may be possible. The earlier studies from the 1990s in developing countries [34, 35] show women using personal information sources first when seeking information for many reasons including health related. The later studies, and studies from developed countries [36-40, 42-47], indicate that women, both in developed and developing countries, seek a majority of health-related information from their healthcare providers. The one study of adolescents, girls and boys, shows a majority of these young people from sub-Saharan Africa use mass media sources in addition to school and personal sources to meet their reproductive and sexual health needs [41]. The theme that comes through all of these studies is the idea that pregnant women and mothers from all

different societies, both developing and developed, show a preference for receiving health information from a person, whether a healthcare provider or not. Mothers in the population of adolescents in sub-Saharan Africa [41] appear to be the main exception to that finding.

## **B. Maternal and/or Child Healthcare Record**

### **1) Healthcare Providers Information Needs**

The articles listed in [Table 3](#) are, for the most part, descriptions of various forms of the maternal and/or child healthcare record, and describe the specific information needs of maternal and/or child healthcare providers as they offer suggestions for the data set and format important to collect to provide appropriate prenatal and early childhood care. It seems clear that development proceeded over a number of years to arrive at the most current versions of the maternal and child record in developing countries [27, 31]. Currently these records are individualized for each country or region, but include information such as: the names of the mother, father and child; the child's date of birth; antenatal examination findings; recommended vaccination and prophylactic therapy schedule for the mother and child; growth charts for both the child and pregnant woman; varying levels of advice for care during pregnancy and young childhood; as well as location specific physical parameters and findings such as maternal blood pressure, maternal hemoglobin and child's developmental and nutritional status.

**Table 1.** Health information needs studies (concerning mothers, women/families and/or reproductive health) in developing countries

Study	Type of study (Number of participants)	Research question*	Results *
[34] Fairer-Wessels FA. 1990.	Qualitative survey and interview (#80)	What are the daily information needs of urban black South African women, are they generally able to fulfill those needs, how and where do they search and would development of Community Information Centers help?	Generally these women use <b>interpersonal</b> sources for seeking information needs, and the most commonly sought information is regarding health issues. A community information center sounds like a good idea (no reasons really offered).
[35] Ngimwa, P, et al. 1997.	Qualitative survey and interview (#312)	What is the media accessibility and use of rural women in Kenya? Additionally what are their main information needs and information sources?	The women in this study tend to use <b>interpersonal</b> sources of information most frequently (60% use friends and relatives, and 34% use professionals as a first information source, with 74.1% expressing satisfaction with source) and the researchers recommend alternative methods for providing information to these women rather than media like radio. Women tend to have most questions about healthcare needs (43.3%) and farming/agricultural issues (29.8%).
[36] Lugina HI, et al. 2001.  [37] Lugina HI, et al. 2004.	Qualitative survey interview (#110)  Qualitative interview + card sorting activity (#110)	What are the concerns of first time mothers in Dar Es Salaam, Tanzania immediately and six weeks post-partum?  What are mothers concerns regarding the post-partum period, and are there better methods for getting at the	In this population, some maternal worries change over six weeks, some stay the same. Worries were mainly around the baby's general condition (with lesser concern about care and behavior) and the mothers' feelings (with lesser concerns regarding appearance, family reactions, and sexuality), switching to more interests and confidences in these areas after 6 weeks. Questions are raised about how to provide timely



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		information in developing countries?	<p>information. Overall between 1-6 weeks post partum, worries decrease from 29%-15% (about baby from 31%-14% &amp; self from 30%-20%) and interests (overall 38%-42%, baby 41%-50%, self 38%-41%), and confidences (overall 32%-43%, baby 29%-36%, self 32%-39%) increase. This study will help <b>healthcare providers</b> to understand the types of information these women are looking for post-partum.</p> <p>Additionally, using card sorting seems to get better response than just interview alone for concerns, interests, etc. of first time mothers.</p>
[38] Mooko, N. P. 2005. [39] Mooko, N. P. 2002.	Qualitative interview and focus groups (#60)	What are the information needs and information seeking behaviors of rural Botswanan women?	The most common information need of women in the study related to health information for the women and their families, and the most common and helpful information source was a <b>healthcare provider</b> .
[40] Ertem IO, et al. 2007.	Random survey and interviews (#1200)	What do mothers in a developing country (Turkey) know about young child development?	In general, mothers felt that developmental milestones occur later than actual for normal children- the majority of women did not know that sight (52%), vocalization (79%), social smiling (59%), and overall brain development (68%) begin in the early months of life. Women with more education and fewer children had a better idea of actual childhood development. This study suggests that <b>healthcare providers</b> need to educate mothers in child development for optimum provision of pediatric healthcare.
[41] Bankole A, et al. 2007.	National household survey	What is the knowledge level of young teens in four sub-Saharan countries (Burkina Faso, Malawi, Uganda, and Ghana),	These kids use multiple information sources, most commonly <b>mass media</b> (45.6%-78.9% depending on gender and country), but also teacher/school (17.7%-69.8%, depending on gender and country) and friends

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		and how do they fill their information needs regarding sexual behavior, STIs and pregnancy?	(18.2%-59.7%, depending on gender and country). The researchers suggest that in-school education programs might be most effective.
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\* See [notes](#) regarding research question(s) and results

**Table 2. Health information needs studies of mothers (particularly disadvantaged mothers) in developed countries**

<b>Study</b>	<b>Type of study (Number of participants)</b>	<b>Research question*</b>	<b>Results*</b>
[42] Green JM, et al. 1990.	Prospective survey (#825)	How do expectations of childbirth coincide with satisfaction, especially in the realm of feelings of control and adequate information reception on the part of the mother (southeastern England)?	In this study, high expectations did not seem to lead to poor outcomes, and lower expectations seemed to lead to less satisfaction. Women wanted to retain control as much as possible and many reported that greater information given to them by their <b>healthcare providers</b> about what to expect led to a greater feeling of control.
[43] Baker LM, et al. 2007.	Qualitative interviews (#30)	What are the health literacy levels, and information seeking behaviors toward the vaccines given to their children of this group of mothers?	In this very small sample, most of the women were unaware of the purpose of the vaccines their children were receiving (26 of 30). Health literacy levels of this group of Detroit mothers were relatively low, and they tended to receive their information regarding their children's vaccines from the <b>healthcare provider</b> (22% from doctors, 18% from clinic nurses, the rest from 1-9% from 10 other sources).
[44] Smith SK, et al. 2009.	Qualitative interviews (#73)	How do education levels and health literacy affect people's information needs and expectations for health decision-making?	In this population from Sydney, Australia, more highly educated/health literate patients seem to take a higher responsibility for making their own decisions regarding health care, whereas less educated patients relied more on health care providers to make decisions to which they would either agree



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			or disagree.
[45] Shieh C, et al. 2009.	Standardized test of health literacy and interview (#143)	How do health literacy levels relate to the use of health information sources and barriers to information seeking in low-income pregnant women in urban Midwestern U.S.?	Higher levels of health literacy were related to a greater ability to use multiple information sources with lower barriers to information seeking. Results suggest that information seeking skills should be taught to patients with lower health literacy. Both the high (85.3%) and low health literacy (14.7%) group used <b>healthcare professionals</b> most frequently (low 90.5%, high 74.6%), with books/brochures (low 57.1%, high 58.2%) and family and friends next most frequently (low 57.1%, high 51.5%).
[46] Shieh C, et al. 2009.	Qualitative interviews (#84)	What are the information seeking behaviors (information needs and barriers) in this population of low-income pregnant women?	In this urban Midwestern U.S. population it was shown that information seeking was highest in those women with the highest needs (asthma and first pregnancy) and the lowest barriers to obtaining information. Also showed that <b>healthcare providers</b> were the highest source of information.
[47] Shieh C, et al. 2010.	Survey and standardized testing (#143)	Do health literacy, positive measures of mother's fetal locus of control and maternal self-efficacy correlate positively with health information seeking in this Midwestern U.S. population of low-income pregnant women?	Feelings of maternal control toward fetal wellbeing ( $r=0.27$ , $p=0.003$ ) and self-efficacy ( $r=0.33$ , $p=0.0004$ ) were positively correlated with maternal information seeking. Health literacy was not ( $r=-0.05$ , $p=0.63$ ). In this study, low health literacy was correlated with a feeling of lowering self-fetus control, in other words, these pregnant women tended to rely on information from <b>healthcare providers</b> more than women with higher health literacy.

\* See [notes](#) regarding research question(s) and results

**Table 3.** Maternal and/or child healthcare record information needs of providers

Study	Type of study/document	Research question*	Results*
<b>Studies of Patient-Held Records</b>			
[48] Hartfield VJ. 1973.	Descriptive	Is there a better method of record keeping for mothers in developing countries?	This is an early proposal for use of card to improve record keeping. Positive outcomes for PHMR suggested.
[49] Dissevelt AG, et al. 1976.	Descriptive	What are features of record to facilitate detection of high-risk pregnancy in rural Kenya?	Earlier Kenyan maternal card, positive benefits suggested.
[50] Sims P. 1978.	Descriptive	What are features of record to facilitate detection of high-risk pregnancy?	Provider information, dense information, not for illiterates, PH card prototype. Positive value felt by author, especially since patient generally has information available- important especially in case of emergency
[51] Shah KP, et al. 1981.	Descriptive	What are features of Indian record to facilitate detection of high-risk pregnancy?	Description of card, apparently useful to help detect risk factors.
[52] Chabot HT, et al. 1986.	Descriptive	What are features of record to facilitate detection of high-risk pregnancy?	Prototype for pictorial card, describing the need for testing and use in Guinea Bissau where most pre-natal care done by Illiterate TBAs. Results unknown. Felt to be necessary and helpful for helping TBAs, but difficult to get right. Suggestions for single card usable for

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			both lit and ill to allow mother to carry only one card. Area determines different procedures done by each.
[23] Kumar V, et al. 1988.	Descriptive	What are features of record to facilitate detection of high-risk pregnancy/improve quality of care in India?	Description of card, apparently useful to help detect risk factors. Benefits of using for illiterate traditional birth attendant (TBA) in order to aid in earlier detection of risks and improved maternal self-care.
[25] World Health Organization. 1992.	Instructional booklet	What are guidelines for implementing home-based child health records?	In depth instructions for implementing PHCR card or booklet. Specifications for how to implement and how to alter to fit the particular circumstances for each area of implementation.
[26] World Health Organization. 1994.	Instructional book	What are guidelines for implementing home-based maternal records?	In depth instructions for implementing PHMR card or booklet. Specifications for how to implement and how to alter to fit the particular circumstances for each area of implementation.

**Studies of Clinic-Held Records**

[53] Poulton EM. 1966.	Descriptive	Reasons for record keeping for maternal child health care in developing countries.	Basic outline of the purpose of records.
[54] Essex BJ, et al. 1977.	Descriptive	What are features of record to facilitate detection of high-risk pregnancy?	Early card for providers' use, not for illiterates, card prototype reminder of need to test

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			against existing. The new card demonstrated a high rate of agreement between providers, and was felt to be useful in Tanzania
[55] Alisjahbana A, et al. 1984.	Observation (#20)	How can we improve traditional birth attendants' (TBA) reporting of high-risk births in Indonesia?	This study showed that TBAs able to report, assess, and respond accurately if trained and risk indicators defined in a way they understood.
[56] Kennedy I, et al. 1984.	Descriptive	What are the reasons for restructuring record in Botswana?	Ability to follow pregnancy by use of an obvious graph to compare between visits seems helpful to catch problems. Not necessarily designed for developing countries

**Studies of Electronic Records**

[57] Moidu K, et al. 1992.	Expert consensus	What is the essential data set of an electronic maternal health record?	Examines feasibility of creating and using the data set, data set listed. Importance is that data set might be different for each location. Data sets being tested in Sweden and India.
[58] Phelan ST. 2008.	Descriptive	What are the comparisons between the current well-organized and useful paper record to an electronic record (U.S.)?	The authors clearly don't want to lose the positive aspects of the pre-natal record that has been working well for a number of years, but recognize the portability and potential for back-up and legibility of the electronic record, while recognizing the inherent difficulties of setting up a new system.

## 2) Patient Held Records

For a number of years, a variety of developed and developing countries have used patient-held maternal health records and/or parent-held child health records [25, 26, 48-52, 59]. More recently, as described above for Kenya [31], countries have started adopting patient-held combined maternal and child health records. These records are frequently designed with guidance from the WHO, though each jurisdiction is encouraged to develop the record best suited to its culture and populace [25, 26].

The literature review results fall into a few categories based on whether utility of the record to the patient/parent (**Tables 4, 5 and 6**) or the healthcare provider (**Tables 7, 8 and 9**) was the main focus of the study; also whether the record was specific for maternal and/or child healthcare or for other types of healthcare. Additionally, findings tended to vary for studies carried out in developed versus developing countries.

### a) Utility to Patients

The majority of results are neutral for the effects of the patient-held maternal and/or child record in the studies conducted in developing countries (**Table 4**). Increasing patient education was felt to be one way to improve the card's utility in all four of the studies with neutral results [59, 61-63], and use and understanding of the card is felt to be key in the two positive outcomes [59, 60]. Where noted, loss of the record was not felt to be a significant issue [59, 63].

In the 13 studies showing a positive outcome for the patient-held maternal and/or child record studies in developed countries [64-76], words like confidence, control, access (better informed), satisfaction, and communication (interaction) were repeated (**Table 5**). In addition, in eight of the nine studies where recorded, there were few or no missing or lost records, and some families retained the records for many years [65-70, 72, 75, 77]. The two studies showing inconclusive or neutral results were focused on the health outcomes of the record [76, 77].

All eleven studies of the patient-held (not maternal and/or child) records were carried out in developed countries (**Table 6**). Results in these studies were variable. The six positive outcomes were qualitative assessments of patient benefit [78-83]. One of the two studies with negative results reports less satisfied patients, and the other reports a potential imbalance of power relationship [81, 82]. The seven studies including neutral results, were just that, the results were inconclusive [82-88]. Where noted, patients are generally willing and able to carry the card [80].

### b) Utility to Care Providers

The care provider is most likely to be influenced by the results in the 15 studies of the patient-held maternal and/or child records in developing countries (**Table 7**). The ten positive results demonstrated here are, for the most part, improved outcomes in healthcare results or

preventative measures such as detection of risk, quality of care, higher rates of care, as well as increased educational opportunities [24, 63, 89-96]. The six studies with neutral results can show no conclusive positive results, but provide a positive overall feeling toward the record [61, 96-100]. In studies where noted, the majority of women were able to keep track of the record even if they weren't always brought to healthcare provider visits [63, 92, 94, 96].

The seven studies of patient-held maternal and/or child records from developed countries ([Table 8](#)) show results that most likely to influence care providers. These outcomes offer a more mixed view of the effects of the records. Definite positive benefits were shown with children's immunizations [69, 101], return of record following education about its importance [103], and impressions of improvement in communication, access and care [68, 102]. Neutral results center on management of the record [69, 103] and inconclusive health results [76]. Negative results arise from confidentiality concerns, increase in burden of work, size of the record, and increased surgical intervention [68, 76, 104]. This final concern noting increased surgical interventions with possession of the patient-held record might be considered positive in developing countries where detection of risk factors and elucidating the need for referral are crucial to the records' function [89-92]. The majority of patients were able to produce records when requested in studies reporting this factor [68, 69, 103].

The three final studies ([Table 9](#)) of the influence on care providers of the patient-held (not maternal and/or child) records show some positive benefits in compliance in patients with possession of the record [81], though the other two studies demonstrate the patients just not using or carrying the record [105, 106].

The studies listed in **Tables 4-9** delve into the usefulness of and outcomes for the patient-held record. In total, 48 studies were listed in the six categories of type of patient-held record: (maternal and/or child or not,) care provider or patient most influenced/effected, and research done in developed or developing country. Nine (one study in two categories) of the studies are felt to have mixed results [59, 68, 69, 76 (twice), 81-83, 96, 103], and six of the studies are felt to concern both patient and care provider [61, 63, 68, 69, 76, 81]. Of these results, 37 show positive effects or influences, 24 show neutral effects or influences, while only five studies show negative effects or influences produced with use of a patient-held health care record.



**Table 4. Who studied: what studied – where**

**Patient: Patient held maternal and/or child records - developing countries**

	Type of study	Research question*	Results (positive outcome of having record)	Results (neutral)	Results (negative outcome of having record)
[60] Kusumayati, A, 2007.	Repeated cross-sectional survey (#611, #621, #630)	What are the effects of the MCH in Western Sumatra on using maternal health services?	The mothers using (not simply owning) the MCH had 2.5 times better knowledge of the benefits of some pre-natal care measures, and were 3 times more likely to seek out needed care.		
[59] Nakamura Y 2010.	Descriptive	What is the history of the MCH Handbook in Japan?	This study included here, as the MCH Handbook was first distributed in Japan in 1947. The positive benefits of the MCH Handbook include ease of	The main concerns are the costs (though less than multiple separate cards), the fear of loss (not found to be a significant problem), and the uneven use of the cards	

			understanding, access to child and maternal health information, and having records available when needed.	depending on the quality/amount of care available.	
[61] Harrison D, et al. 1998.	Descriptive / interview (#185)	What are the opinions of mothers/caregivers (#150) and health care providers (#35) regarding accuracy and completeness of the Road to Health card in Cape Town, South Africa?		Health care providers like the concept, but would like information to be in a more useful format. Points out need to determine what information is important to family and healthcare providers in order for them to actually fill out all information.	
[62] Mahomed K, et al. 2000.	Descriptive /interview (#51)	How feasible is having a PHMR in rural Zimbabwe, and do mothers understand the reasons for the record?		The introduction of the record seems feasible, but much more education of mothers is	

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				needed for them to understand value as only 49.1% returned at end of study.	
[63] Tarwa, C., et al. 2007.	Survey (#300)	Is the South African Road-to-Health card brought to consultations and used by health care providers?		The RTH card is not brought to 48% of consultations. Adults mostly (72%) thought they were only to bring the card to well-baby clinics. Care providers are missing an opportunity to educate and provide health monitoring.	

\* See [notes](#) regarding research question(s) and results

**Table 5. Who studied: what studied - where**

**Patient: Patient held maternal and/or child records - developed countries**

	Type of study	Research question*	Results (positive outcome of having record)	Results (neutral)	Results (negative outcome of having record)
[64] Draper J, et al. 1986.	Case controlled survey (#171)	What are Cambridge (UK) women's views on carrying MHR?	Generally positive view (71/88 liked carrying record; 83/88 thought there were advantages), women appreciate <b>access</b> to information.		
[65] Elbourne D, et al. 1987.	Randomized controlled trial (#290)	What are women's preferences for carrying own MHR (Oxford)?	Positive effects of carrying more complete record as opposed to notes are: possibly decreased clerical time, a greater sense of feeling of <b>control</b> , <b>confidence</b> talking with medical personnel. No increase in lost notes over system.		
[66] Lovell A, et al. 1987.	Randomized controlled trial (#246)	What are women's preferences for carrying own MHR (London, UK), and does carrying own increase satisfaction with care?	Positive effects of carrying more complete record as opposed to notes are: possibly decreased clerical time, increased feeling of <b>control</b> . Decrease in lost/mislaid notes (0 for PHMR) over system (25%).		
[67] Saffin K, et al. 1991.	Case controlled survey (#452)	How well are children's records kept by parents, and do parents who have PHR (#284) and those who don't (#168) prefer to keep their children's records (Oxfordshire)?	Parents who kept their children's records had more positive view of practice (75% PHR vs. 26% non-PHR. Appreciated <b>access</b> , 90% PHCR available for audit.		

[68] Charles R. 1994.	Survey and case control comparison of physical records (#155)	Is the parent held record an effective means of communication, does it derive any benefit if yes, and is the North Staffordshire PHR a good quality source of patient information for parents (#100) and professionals (#55)?	The vast majority of parents (87-99%), nurses (67-100%) and health visitors (70-100%) agreed with a smaller majority of doctors (53-78%) that the child's individual record plus the information on child healthcare helped improve <b>communication</b> and care in at least 3 areas. Audits compared to clinic held records revealed significantly more information recorded on the parent held record.		
[69] Jeffs D, et al. 1994.	Random sample interview (#622)	Are PHR retained and used to appropriately to record immunizations, and are parents and providers satisfied with their use (New South Wales)?	The majority (93%) of parents retained their records, with the majority having at least one (91%), and a smaller majority (68%) having all immunizations recorded in the record by. The majority of providers are (80-90%) satisfied with the use of the record.		
[70] Webster J, et al. 1996.	Descriptive /survey (#200)	What are women's preferences for carrying own MHR in Brisbane, Australia, and does carrying own increase satisfaction with care?	Greater <b>satisfaction</b> with care in PHR group, though 36% forgot record at least once in at least 5 visits. Women felt increased <b>control</b> with PHR.		
[71] Homer CS, et al. 1999.	Randomized controlled trial (#150)	What are women's preferences for carrying own MHR (as opposed to a care card,) and does carrying full record increase satisfaction with care (New South Wales)?	Women tended to feel more <b>confident</b> carrying full record, and reported a significantly greater feeling of <b>control</b> and <b>access</b> to information about their pregnancy; 89% would choose to do so again.		

**Table 5 (continued) Who studied: what studied - where**

**Patient: Patient held maternal and/or child records - developed countries**

	Type of study	Research question*	Results (positive outcome of having record)	Results (neutral)	Results (negative outcome of having record)
[72] Phipps H. 2001.	Qualitative - interview (#21)	What is impact of carrying own record during pregnancy (Sydney, Australia)?	Great majority of women favored carrying their own record in this and subsequent pregnancy, felt themselves and family to be <b>better-informed</b> , minimal worry about losing record.		
[73] Usha Kiran TS, et al. 2002.	Prospective survey (#72)	What are women's preferences for carrying own MHR and is it an increased burden (South Wales, UK)?	The majority (90.2%) of mothers preferred to carry own notes; feeling it improves <b>access</b> to their case notes.		
[74] Shaw E, et al. 2008.	Randomized controlled trial (#193)	Does secure access to pre-natal records lead to higher access to online information and greater satisfaction with care (Hamilton, Ontario)?	Study group <b>accessed</b> pre-natal information much more frequently, and average of 8.6 more log-ins (including own record: 84.2% of time) both groups <b>satisfied</b> with information provided.		
[75] Clendon J, et al. 2010.	Qualitative – interview (#35)	What is the impact of the PHCR in New Zealand	This is a good tool for improving <b>interaction</b> between mother and nurse. Mothers keep the record for years; sometimes pass		



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			them on to child when grown.		
[76] Brown HC, et al. 2004.	Systematic review (3 trials)	What are the effects of having women carry their own case notes during pregnancy?	Positive patient view of more <b>control</b> of care, and an increased sense of <b>satisfaction</b> .	Inconclusive <b>health</b> outcomes	
[77] Bjerkeli Grøvdal L, et al. 2006.	Randomized controlled trial (#309)	Do PHR have positive effect on parents' knowledge, collaboration with or utilization of healthcare in Norway?		No <b>health</b> effect or improvement in other measures noted by parents. Majority of parents carried record.	

\* See [notes](#) regarding research question(s) and results

**Table 6. Who studied: what studied - where**

**Patient: Patient held records in general - developed countries**

	Type of study	Research question *	Results (positive outcome of having record)	Results (neutral)	Results (negative outcome of having record)
[78] Giglio R, et al. 1978.	Descriptive /survey (#30)	Are people interested in carrying their own PHR (Amherst, MA)?	Study shows that patients are <b>willing</b> to make the effort to carry own card, further study needed to determine if makes a difference in outcomes		
[79] Liaw ST, et al. 1998.	Randomized controlled trial (#72)	What is the impact of a PHR on responsibility, information sharing and preventative health care of patients holding a PHR in Adelaide, Australia?	Statistically <b>significant improvement</b> noted in responsibility and information sharing of patient, and may help patient awareness/participation in own care.		
[80] Jerdén L, et al. 2004.	Descriptive /survey (#418)	To what extent do patients report a lifestyle change when they have a PHR?	Swedish study indicates <b>positive lifestyle changes</b> in 25% of those patients who received an informative health booklet (and record)		
[81] Dickey LL. 1993.	Literature review (#7 trials)	Have studies shown any benefit to PHR for preventative care?	Some <b>positive benefits</b> for patient involvement in their own care in the majority of studies. Immunization records for children seem to show the highest positive value. <b>Future possibility of electronic mini-records.</b>		<b>Potential barriers</b> include disruption of traditional power barrier, and perception of increased time required.

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[82] Lecouturier J, et al. 2002.	Randomized controlled trial (#189)	Does holding own record increase cancer patient satisfaction and positive feelings about communication with care provider (Newcastle-upon-Tyne, UK)?	Healthcare staff had <b>positive</b> impression.	53% with PHR found it helpful.	Patients with PHR less <b>satisfied</b> (58% vs. 86% very satisfied) with information given, perhaps due to higher expectations.
[83] Williams JG, et al. 2001.	Randomized controlled trial (#501)	Do patients feel PHR improves quality of life (Wales, UK)?	<b>Improved</b> sense of control of cancer management for some patients.	<b>No demonstrated improvement</b> in quality of life for cancer management. 52% of patients would have preferred not to have PHR.	
[84] Drury M, et al. 2000.	Randomized controlled trial (#650)	Does holding own record increase patient satisfaction (Oxford)?		<b>No demonstrated improvement</b> in satisfaction for cancer management.	
[85] Cornbleet MA, et al. 2002.	Randomized controlled trial (#244)	Does holding own record increase cancer patient satisfaction in urban Scotland?		Patients like it, but <b>no difference</b> noted on patient satisfaction and imposing on the providers on top of other records may be too much on workload.	

Table 6 (continued) Who studied: what studied - where

## Patient: Patient held records in general - developed countries

	Type of study	Research question*	Results (positive outcome of having record)	Results (neutral)	Results (negative outcome of having record)
[86] Lester, H, et al. 2003.	Randomized controlled trial (#201)	Do patients in Birmingham, UK feel that PHR improves outcomes?		<b>No good evidence</b> that PHR helped schizophrenics, but not apparently harmful, and a higher symptom score was associated with not having record.	
[87] Gysels M, et al. 2007.	Systematic review (#12 studies)	Do PHR improve patient satisfaction with communication and information exchange?		Extensive literature review into efficacy of PHR to improve patient satisfaction for specific cancer patients. Random controlled trials show different outcomes ( <b>negative/neutral</b> ) than qualitative studies that show a more <b>positive</b> outcome. Provider attitude and use of PHR seems important in outcome and efficacy.	
[88] Ko H, et al. 2010.	Systematic review (#14 trials)	Is there any improvement in outcomes or patient satisfaction with PHR in chronic disease management?		<b>No demonstrated improvement</b> in patient satisfaction measures and communication or care outcomes with holding PHRs in chronic disease management in developed countries.	

\* See [notes](#) regarding research question(s) and results

**Table 7. Who studied: what studied - where**

**Care Provider: Patient held maternal and/or child records - developing countries**

	Type of study	Research question*	Results (positive outcome of having record)	Results (neutral)	Results (negative outcome of having record)
[89] Kumar V, et al. 1981.	Descriptive (TBAs from 15 villages)	What are features of record to facilitate detection of high-risk pregnancy in India?	Description of card, apparently useful to help <b>detect risk factors</b> . Benefits of using for illiterate TBA in order to aid in earlier <b>detection of risks</b> .		
[90] Watson DS. 1984.	Descriptive survey (#53 notes in 1980-81 and #60 in 1982-83)	What are features of record to facilitate detection of high-risk pregnancy?	Early record for in-clinic use by Australian Aboriginal health workers. Equivalent results to normal records, results are <b>positive</b> .		
[91] Abraham S, et al. 1985.	House-to house survey (#400)	What features of record are needed to improve quality of care and improve record keeping (Vellore, India)?	MCHCC evaluation reveals positive effects on <b>quality of care, detecting risks</b> . Improvement needed in stressing importance for educating mothers/families, as 7% of mothers lost record and 18% discarded it following sterilization.		
[92] Abraham S, et al. 1991.	Non-randomized control (#2446)	Does provision of PHMR card improve outcomes in pregnancies in rural India?	Some positive outcomes for <b>referral</b> and <b>knowledge</b> of people involved-knowledge higher for most measures in women with PHMR. Good acceptance by families, but suggestions for greater acceptance.		
[24] Shah PM, et al. 1993.	Large, multi-center collaborative comparative pre/post intervention study (#13 in #8)	Evaluate the function of the PHMR following set of WHO guidelines.	Substantial improvement in maternal and neonatal <b>care</b> , and continuity of care in areas using PHMR (examples: Philippines 91-100% vs. 36.6-51.9%; Zambia 93.5% vs. 49.8%). Records adapted to local situation.		

	countries)		Improvement noted in maternal <b>knowledge</b> for self care.		
[93] Daly AD, et al. 2003.	Interview survey (for #177 children and #220 women)	Do opportunities for vaccination get missed in Swaziland?	In this study, children and adults with health card present <b>less likely to be a missed</b> opportunity for vaccination.		
[63] Tarwa, C., et al. 2007.	Survey (#300)	Is the South African Road-to-Health card brought to consultations and used by health care providers?	The RTH card is not brought to 48% of consultations. Adults mostly (72%) thought they were only to bring the card to well-baby clinics. Care providers are missing an <b>opportunity to educate</b> and provide health monitoring.		
[94] Corrigan J, et al. 2008.	Household survey (#3705)	What is level of routine immunization coverage in the Western Cape?	In this study, possession of Road to Health card is highest predictor for <b>vaccination coverage</b> , and children possessing the card were 39.5 times more likely to be vaccinated.		
[95] Osaki K, et al. 2009.	1997 and 2002/3 Indonesian Demographic and Health Survey	What is level of routine immunization coverage?	Ownership of MCH booklet positively associated with young children's full <b>vaccine coverage</b> (70.9% vs. 42.9%) in Indonesia.		



**Table 7 (continued) Who studied: what studied - where**

**Care Provider: Patient held maternal and/or child records - developing countries**

	Type of study	Research question*	Results (positive outcome of having record)	Results (neutral)	Results (negative outcome of having record)
[96] Mukanga DO, et al. 2006.	Random household interview survey (#260)	What factors contribute to family having and retaining PHCR in Uganda?	There is a positive relation to <b>improved health</b> with card retention. Children with a card were 10 times as likely to be <b>fully immunized</b> .	Mothers don't receive card as frequently if they don't use a health care center. Children delivered at a healthcare facility were 4 times as likely to have card; children who had been to a facility in the past 3 months were 2 times as likely to have card.	
[97] Chabot HT, et al. 1990.	Literature review and descriptive survey	Would including pictorial and written risk indicators make a single PHMR more useable for ALL prenatal caregivers?		Includes literature review of current MHR in use and suggestions for single card usable for both literate and illiterate health care providers to allow mother to carry only one card. Area determines different procedures done by each. Example from Mali.	
[98] Kumar R. 1993.	Descriptive/ interview (#14)	Does the simplified MHR improve workload and improve statistical reporting in rural India?		The simplification decreased the workload for healthcare workers, but no or minimal improvement in	

				reporting of vital statistics.	
[99] Goldman N, et al. 1994.	Data from the 1987 Encuesta Nacional de Salud Materno Infantil (National Survey)	How does the official government record of immunization in Guatemala compare with PHR and maternal recall for obtaining a more accurate view of immunization levels?		Compares (with great limitation) data obtained from the card as opposed to maternal recall-is likely to be at least as/or more accurate than the government (potentially overestimated record).	
[61] Harrison D, et al. 1998.	Descriptive / interview (#185)	What are the opinions of mothers/caregivers (#150) and health care providers (#35) regarding accuracy and completeness of the Road to Health card in Cape Town, South Africa?		Most health care providers (80%) support the concept, but most (80%) would like information to be in a more useful format. Points out need to determine what information is important to family and healthcare providers in order for them to actually fill out all information.	
[100] Nuwaha F, et al. 2000.	Retrospective comparison of national survey	Did immunization levels improve after introduction of vaccination cards and Vitamin A supplementation in Uganda?		Immunization cards may have been seen as proof of vaccination and caring parent. People with cards seemingly get better care. Vaccine levels increased after introduction of cards and vitamin A supplementation, though causality could not be determined.	

\* See [notes](#) regarding research question(s) and results

**Table 8. Who studied: what studied - where**

**Care Provider: Patient held maternal and/or child records - developed countries**

	Type of study	Research question*	Results (positive outcome of having record)	Results (neutral)	Results (negative outcome of having record)
[101] McElligott JT, et al. 2010.	Government-provided data analysis	Are PHR for childhood immunizations positively correlated with being up-to-date on vaccines?	In US, especially with more disadvantaged families, holding vaccination record associated with <b>higher rates of immunization</b> ; odds for child being up-to-date determined as 62% greater for children with PHR.		
[102] MacFarlane A, et al. 1990.	Retrospective study (#239)	What are the reactions of general practitioners and health visitors of PHCR?	In Oxfordshire, the majority of providers (over 90%) with experience with PHR have positive response to PHCR due to ability to <b>access information</b> , minimal experience of loss. Providers <b>WITHOUT</b> experience much more uncertain, only		

			59% view PHR positively.		
[103] Toohill J, et al. 2006.	Audit /survey (#1256)	Are PHMR returned with mother at time of delivery, and does education improve return rate (Australia)?	The majority of mothers returned their records. Compliance numbers increased over time with education on importance of recordkeeping (82 to 88.5% increase in <b>compliance</b> ).	There were some issues for healthcare providers for <b>maintaining</b> record completeness if record not available.	
[69] Jeffs D, et al. 1994.	Random sample interview (#622)	Are PHR retained and used to appropriately to record immunizations, and are parents and providers satisfied with their use (New South Wales)?	The majority (93%) of parents retained their records, with the majority having at least one (91%), and a smaller majority (68%) having all <b>immunizations recorded</b> in the record by. The majority of providers are (80-90%) satisfied with the use of the record.	A smaller than hoped for number of providers (29-79%) had the <b>purpose</b> of the PHR explained to them, and a wide range in the professionals who used the records (30-96%).	

[68] Charles R. 1994.	Survey and case control comparison of physical records (#155)	Is the parent held record an effective means of communication, does it derive any benefit if yes, and is the North Staffordshire PHR a good quality source of patient information for parents (#100) and professionals (#55)?	The vast majority of parents (87-99%), nurses (67-100%) and health visitors (70-100%) agreed with a smaller majority of doctors (53-78%) that the child's individual record plus the information on child healthcare helped <b>improve communication and care</b> in at least 3 areas. Audits compared to clinic held records revealed significantly more information recorded on the parent held record.		Doctors expressed concerns about maintaining <b>confidentiality</b> , extra burden of <b>work</b> in maintaining the records, the size of the record and fears that patients wouldn't bring the record to clinic visits (this final concern may be dispelled by the increased amount of information recorded in the PHR).
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Table 8 (continued) Who studied: what studied - where

## Care Provider: Patient held maternal and/or child records - developed countries

	Type of study	Research question*	Results (positive outcome of having record)	Results (neutral)	Results (negative outcome of having record)
[76] Brown HC, et al. 2004.	Systematic review (3 studies)	What are the effects of having women carry their own case notes during pregnancy?		<b>Inconclusive health outcomes.</b> Providers report an increase in the number of surgical interventions with women carrying their PHR. <i>This might be a positive finding in developing countries where the problem is lack of intervention in high-risk cases.</i>	Providers report an increase in the number of surgical interventions with women carrying their PHR. <i>This might be a positive finding in developing countries where the problem is lack of intervention in high-risk cases.</i>
[104] Wilkinson SA, et al. 2007.	Descriptive - survey (#7) /review discussion (#25+)	What are the effects of having women carry a <b>new</b> enhanced record during pregnancy (Queensland)?			Care providers felt that the <b>new</b> record was too large for the patient to carry, and contained too much information to be useful to mother. Suggested a smaller patient-centered document for mother, and full record to be kept in clinic.

\* See [notes](#) regarding research question(s) and results



**Table 9.** Who studied: what studied - where

**Care Provider: Patient held records in general - developed countries**

	Type of study	Research question*	Results (positive outcome of having record)	Results (neutral)	Results (negative outcome of having record)
i. [81] Dickey LL. 1993.	Quasi experimental comparison (#25)	Is patient compliance with preventive care guidelines improved with PHR (San Francisco, CA)?	Some positive benefits noted by 54-82% of care-providers for 7 separate parameters, with increased compliance providing preventative care in study groups (9.3-11.6% higher compliance than control).		
[105] Atkin PA, et al. 1995.	Prospective survey (#187)	Are medication PHR cards used (Sydney, Australia)?		For older population in Sydney, Australia, medication cards don't seem to be used (presentation of card dropped from 61% to 23% over 12 months) or improve compliance in research population (21% of users said card helpful).	

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[106] Dijkstra RF, et al. 2005.	Randomized controlled trial (#769)	Does PHR improve quality of care for diabetes patients in the Netherlands?		Modest improvements in patient health parameters. Disappointing results on maintaining card, 36% using card at end of study.	
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\* See [notes](#) regarding research question(s) and results

## Discussion

### A. Maternal Information Behavior

Though the number of information behavior studies located in this literature review is quite limited [34-47], the sense one gets from them is that families, in particular mothers in developing countries, are interested in information about healthcare issues for their family. While these studies come from different countries and regions of the world, they show some interesting similarities. Generalization of mothers' information behavior is not possible due to the small number of studies and participants. In the studies that measure all types of information seeking behavior, health information needs rank high in the list of overall women's information needs in developing countries [34, 35, 38, 39]. The few studies that look specifically at health information seeking behavior in these populations [36, 37, 40], show that mothers studied in the developing countries tend to seek medical information and advice for their children and families more commonly than searching for other information needs, and the first or most common source for information comes from other people. There is some indication that these mothers are interested in information regarding child development and care. Another common theme in the studies from both developed and developing countries is that mothers from diverse backgrounds prefer to receive health information directly from their healthcare provider. The one exception to this might be mothers in the population of adolescents in sub-Saharan Africa [41], though it is also possible that the nature of the information or the population involved lends itself to a different preferred mode of delivery.

These findings lead one to consider very carefully how mothers might use a home-based healthcare record as a source of information regarding their own and their children's care. The literature retrieved in this review puts forward the idea that pregnant women and mothers from all different societies, both developing and developed, show a preference for receiving health information from a person, whether a healthcare provider or not. It seems likely, that unless there is a demographic shift in information behavior, mothers may not choose to use information provided in any format of healthcare record. Instead they may continue to seek out interpersonal sources.

### B. Maternal and/or Child Healthcare Record

The earliest studies retrieved regard maternal and child healthcare records in developing countries, and mainly consist of how-to diagrams with the care provider/designer demonstrating their ideas about creation of these records. Due to the descriptive nature of most of the articles listed in **Table 3**, the assumption was made that they reflected the information needs of their healthcare provider and agency creators. The information needs of healthcare providers and other healthcare agencies must be inferred from the proposals and guidelines developed for the production of maternal and/or child healthcare records. The progression shows some measure of the evolution of these records over time [24-26, 47-52].

The other studies retrieved from the search in all categories (**Tables 4-9**), delve into the usefulness and outcomes of the patient-held record. Very few negative results noted for either healthcare provider or patient in the patient-held record. In the patient-effected categories

(**Tables 4-6**), the most patient-noted positive effect in developing countries was the increased knowledge of the benefits of healthcare, as well as having the records available when needed [59, 60]. A lack of understanding of the record's use pointed to a need for greater education in studies where the patient effect was neutral [61-63]. The effect of the patient-held record seems most positive on patients holding maternal and/or child records in developed countries. These mothers, for the most part, tend to relate positive feelings of confidence, control, access (feeling better informed), satisfaction, and improved communication and interaction during the healthcare process (**Table 5**). As mothers in developing countries become better informed and want to play a greater role in their own care, perhaps carrying their own maternal/child records can engender these same feelings. In contrast to mother and child records, most other patient held records have not shown to be of significant benefit to either the patient or the healthcare provider (**Tables 6 and 9**).

The results for the influence of patient-held records on care providers was more mixed (**Tables 7-9**). Care providers in developing countries seemed to recognize the most positive outcomes in terms of improving health and prevention practices with patients carrying the maternal and/or child record (**Table 7**). Though follow-up study needs to continue, the improvements noted for patients are encouraging. In addition, the majority of studies, where this was measured [59, 63, 65-70, 72, 75, 77, 80, 91, 94, 96, 103], showed that patients tend not to lose patient-held maternal and/or child records, though some of the general patient-held records were more readily lost to follow-up [105, 106]. This finding seems significant and may be worth continued study in determining the importance of these records, especially to families in developing countries.

In general, these studies show some positive outcomes related to the use of the patient-held maternal and/or child record. The most positive effects relate to the patient's (mother) emotional state and feelings of control and access to information, particularly in developed countries, and results of improved health outcomes with the patient-held maternal and/or child record in developing countries. The fact still remains that 49 of the 68 priority countries are not on track to reach the UN Millennium Development Goals for 2015 [15], and these positive results need to be further leveraged to help developing countries meet their goals for decreasing mortality and improving health.

### Study Limitations

The results obtained in the literature review may have suffered, both from the inability to find all applicable research in the field, as well from a limited time frame for study. In particular, it was impossible to pursue all potential sources for research in information behavior and patient-held records. The research questions addressed in the studies on patient-held records retrieved from the literature search were quite varied, and therefore difficult to compare aside from impressions of the effect or influence of the record on the patient and/or care provider. In addition, several of the studies produced mixed results, further confusing the comparison. Finally, reviewer bias, access to articles and limitations to the English language inevitably factored into which search avenues were pursued and which articles were included in the study.

## Recommendations

The information behavior of women, particularly in developing countries, needs further investigation. It is unclear whether the childcare and healthcare information provided in existing patient held, maternal-child healthcare records, such as the Kenyan *Maternal & Child Health Booklet* [31] and others [27], meets the needs of mothers and families. The literature suggests that pregnant women and mothers (**Tables 1** and **2**) prefer to seek information from human sources. In particular, mothers appear to prefer to receive information from healthcare providers. Healthcare providers must also be included in any discussion of maternal-child healthcare records; providers' input on needed data is crucial to the success of any healthcare record (**Table 3**).

Several studies have demonstrated the use of mobile technology, such as cell phones and personal digital assistants (PDA), in healthcare in both the developed [105-111] and developing [112-115] world. Protocols have been developed for creating healthcare forms and questionnaires for small mobile devices [114, 116-118]. The technology currently exists for enhancing patient-held records for storage on web-enabled mobile devices [113, 119]. Healthcare providers currently use short message services (SMS) to send targeted health-related messages to their patients [109, 115, 120]. In addition, electronic devices allow for communication beyond just text and the pictorial representation allowed by paper records; cell phones allow for photographic and graphic visual display, as well as voice and text messaging, electronic storage, and two-way capabilities [121, 122]. The next step in evaluating the appropriateness of web-enabled cell technology for a patient-held maternal-child healthcare record in developing countries is to determine whether a mobile platform can meet the information needs of women and families, as well as the healthcare providers in the region. Currently a pilot study is underway in Peru to “[d]evelop an interactive computer-based system and a common mobile phone-based platform to support maternal and child care among pregnant women” [123]. This project, a public-private partnership, also hopes to improve health services to pregnant women by increasing access to timely information, allowing greater monitoring capability by the health system, and finding empirical evidence of the social and economic impacts of mobile technologies. Going forward, further research is needed to explore the utility of providing targeted health messages to mothers regarding their own health and that of their children. Additionally, an assessment of the infrastructure and current practices must be complete to determine if this might best be accomplished through mobile technologies [124, 125].

## **Conclusions**

Information behavior of women, in particular disadvantaged pregnant women and mothers in developed and developing countries and other caregivers in developing countries, seems to rely most commonly on seeking information from interpersonal sources. For health-related information, most of these women look to healthcare providers. More study is necessary to determine if delivering health information in an alternative format would be acceptable or well received.

The development of maternal-child healthcare records in developing countries over time offers the best insight into the basic information needs of maternal-child healthcare providers. The presence of a maternal and/or child healthcare record appears to have a positive effect, for the most part, on both care providers and patients in developing countries. In addition, the presence of a maternal and/or child healthcare record appears to have a positive effect, for the most part, on patients' sense of control and feelings of satisfaction in developed countries. Other types of patient-held records, in developed countries in particular, have not been as positively received.

## **Notes**

Due to space limitations, it was necessary to restate and/or paraphrase research questions and study results listed in the tables above. The first author is responsible for interpreting research questions gleaned from the abstract, introduction and/or problem sections of the articles reviewed. The first author is also responsible for the interpretation and inclusion (or exclusion) of results obtained from the abstract and/or results sections of the articles reviewed.

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